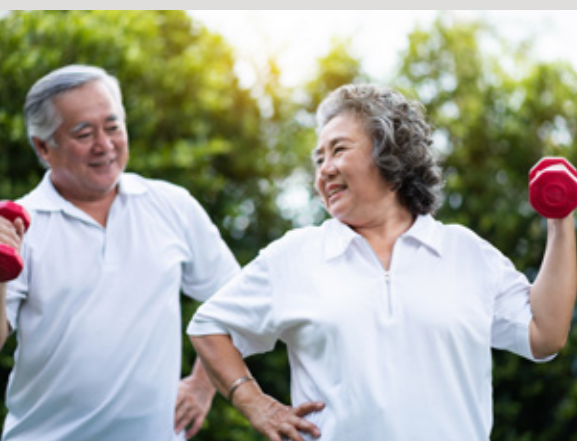
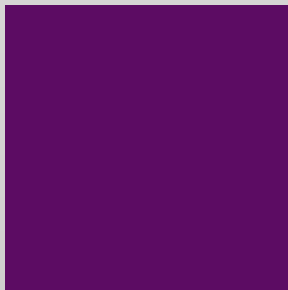
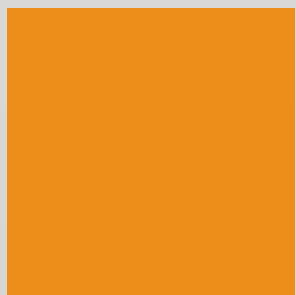


BRAIN INJURY ASSOCIATION OF AMERICA | Volume 16, Issue 2

THE CHALLENGE!



ACCOMMODATIONS THAT WORK



JUNE 2022

THE Challenge! is published by the Brain Injury Association of America. We welcome manuscripts on issues that are important to the brain injury community. Please send submissions in a standard Microsoft Word® document to publications@biausa.org.

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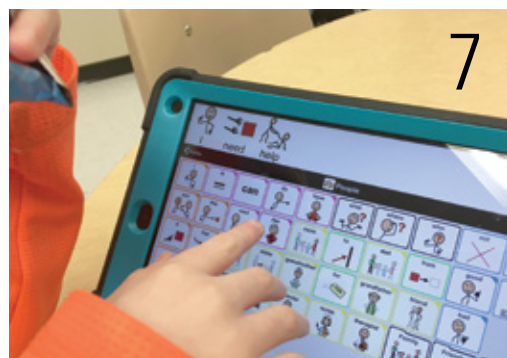
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FROM MY DESK

Earlier this year, the National Academies of Sciences, Engineering, and Medicine issued a new report called *Traumatic Brain Injury: A Roadmap for Accelerating Progress*. On behalf of the Brain Injury Association of America (BIAA), I was honored to provide testimony before the authors who wrote the report and to serve as a reviewer prior to the report's publication. The report is available online. Just visit nationalacademies.org and search for "TBI."

The report examines the current landscape of basic, translational, and clinical TBI research and identifies gaps and opportunities to accelerate research progress and improve care. It offers eight recommendations to transform attitudes, understanding, investments, and care systems for TBI. The recommendations are:

- Create and Implement an Updated Classification Scheme for Care and Research
- Manage TBI as Both a Complex Acute and a Chronic Condition
- Ensure Quality and Consistency of Care
- Enhance Awareness and Understanding of TBI
- Establish an Effective Care System for TBI
- Make the TBI Care System into a Learning System
- Invest in Continued Research
- Provide Leadership to Drive Collaboration and Change

Following the report's release, the National Academies created a TBI Forum to explore opportunities to build awareness, share knowledge, develop policy ideas, catalyze new partnerships, and resolve gridlocks. The Forum will meet two-to-three times per year to address emerging issues in the field.

The National Academies invited BIAA to join the Forum. Through BIAA's membership, I plan to voice the need for better access to appropriate and affordable services and supports, whether provided on a short-term, long-term, or intermittent basis after injury. Such services and supports are essential to returning to school, work, and former social roles.

This issue of *THE Challenge!* is focused on



*Susan H. Connors, President/CEO,
Brain Injury Association of America*

Accommodations that Work. The articles are intended to help readers re-engage in their communities and secure the help and support they need to live well after injury. State brain injury associations serve as important partners in the individual's community reintegration after injury. I encourage readers to review the state news contributed by BIAA's affiliates – they're all doing fantastic work.

I want to take this opportunity to thank BIAA's donors and sponsors. The Association managed to survive the COVID pandemic due to the generosity of many people and organizations. We are grateful to one and all and sincerely appreciate your continued support.

A handwritten signature in black ink that reads "Susan H. Connors".

Susan H. Connors, President/CEO
Brain Injury Association of America



HELPFUL TIPS

Lessons Learned During My Recovery

Tips from Forty Years of Life with a Brain Injury

By Ken Collins

The following are lessons I have learned in my forty years of recovery. They work for me, and I hope that some of them will help you!

- **Take it one step at a time.** You'll get there.
- **Learn from every experience** and move on without dwelling.
- **Slow down and let yourself rest.** Sometimes trying to do too much results in doing nothing at all. Taking a beat to think about an issue may help you figure it out. It may also help you get the energy you need to push past it.
- **Try not to be critical of any mistakes you make.** In the early years of your recovery, there will be too many to count.
- **Reduce stress and anxiety** to make life easier and increase your self-esteem. Mindfulness-based stress reduction strategies can help. Stress and anxiety trigger the fight or flight response; this is beyond your control because it's part of the "emotional nervous system." When fight or flight is activated, you are more likely to be confused and find processing information difficult.
- **Take deep breaths** because nothing works better than getting blood-filled oxygen to your brain. This will also relieve stress and anxiety.
- **Keep an open mind.**
- **Making a to-do list** may help you stay organized. A tablet, smartphone, or just plain paper and pencil can make a real difference. Whatever works for you, use it!
- **Stay calm.**
- **Set a routine.** This will make it easier to follow through with your intentions and stick to a schedule. You may feel more hopeful as you remind yourself of your capabilities.
- **Hope.** Nothing is possible without hope.
- **Eat healthy foods, hydrate, and exercise regularly.** Your body needs energy and blood and oxygen circulating to your brain. Plus, endorphins feel good!
- **Surround yourself with positive people and those who care about you.** Friends who judge and criticize aren't friends. Be careful that negative people don't rub off on your own behavior.



Ken's Story

Ken Collins sustained a traumatic brain injury on December 31, 1976 at his home in Oakridge, Oregon as a result of a snowmobile accident. Over the past 38 years, Ken has become a prominent member of the brain injury community. Among many accomplishments, he served as a founding member of the Oregon Head Injury Foundation and a Board member for the National Head Injury Foundation, has held numerous attendant care jobs as part of Oregon's Client/Employer Program, and was appointed by three Governors to the Oregon Disabilities Commission. Ken currently works at the Hozho Center in Gallup, New Mexico. Learn more at hozhocenterforpersonaleenhancement.com.

Ken Collins, long-time advocate for people with brain injury

- **Don't hold a grudge.** It will tie you down like an anchor.
- **Pay attention.** Become an active listener and watch people's body language.
- **Don't take life too seriously** and don't let the little things get you down.
- **Remember that your family and friends want to help** but sometimes they don't know how. Many people won't understand what you are going through, and sometimes that will mean that they will provide negative feedback or criticism. Try not to hold it against them.
- **Set realistic expectations** for yourself. Don't put up unnecessary obstacles for yourself to overcome.
- **If you can, get a pet.** Taking care of an animal can give you something positive to focus on and relieve stress. I have several dogs. They take me for walks every morning and night and give me unconditional love and companionship.
- **Take an active role in your recovery.** Eliminate the word "can't" from your vocabulary.
- **Get out of your head and into the outside world.** Do something every day to show yourself that you are motivated. Thinking too much about a problem or issue can be depressing. Distract yourself when you start to ruminate.
- **Don't give up.** Push through the adversity and embrace the journey.
- **Enjoy what life has to offer.**
- **Celebrate and take pride in every accomplishment,** no matter how small.
- **Be patient.** Life after a brain injury will get easier.
- **If I can do it, so can you!**

Navigating Assistive Technology (AT)

“For people without disabilities, technology makes things easier; for people with disabilities, technology makes things possible.”

— IBM training manual, 1991



By David Baker

There are many ways to describe the profound impact technology has in the lives of people with disabilities. None is more succinct or prophetic than the quote above.

As technology has advanced, our lives have benefitted; many would argue that they are more comfortable, safer, and even more fun. By text, voice, and video we communicate with family, friends, and colleagues. We bank, order groceries, and visit the doctor from the comfort of our homes. At all hours of the day, we Tweet, post, stream, and “like.” We monitor our health, track our steps, and know from across the globe if we left the garage door open. Technology has made things easier.

For people with disabilities, including many with brain injury, technology has helped restore or improve function and compensate for limitations. It has enabled them to care for themselves and their families, to work, to learn, to access information, and to participate fully in community life. In other words, it has made things possible.

The term most often used to describe technology for people with disabilities is “assistive technology” (AT). AT is an umbrella term that refers to both devices and related services. Wheelchairs and walkers, hearing aids, screen enlargement software, environmental controls,

and aids to daily living that make tasks such as cooking, dressing, and grooming easier are a few examples of the many assistive devices available. Assistive technology services are those activities that directly assist an individual in the selection, acquisition, or use of an assistive technology device. Evaluating an individual for an appropriate device, the provision of device training, and funding assistance are examples.

The effects of brain injury are complex and their impact varies from person to person. What was once easy may now prove difficult due to changes in an individual’s physical, cognitive, sensory, communicative, or behavioral capabilities. The challenges that present themselves provide insight as to where the incorporation of assistive technology might be useful in helping to reduce the consequences of an individual’s changed abilities. The vast array of assistive technology devices available may be overwhelming to individuals new to the field.

As more mainstream companies build assistive features into their devices (e.g., smartphones and tablets) and more mainstream products (e.g., home automation) have applications that can positively benefit people with disabilities, the sense of being overwhelmed only increases. The availability of so many options, though, is on the whole a good situation.

To make the exploration of assistive technology easier, an important first step is to understand the field is often divided into categories or product families, that there is a continuum of assistive technology, and that it's important to match features to products.

HEARING



Devices designed and developed for people with hearing loss that enhance sound or substitute sound with visual or tactile signals.



SPEECH



Speech-generating, voice amplification, and other devices that support expressive language.



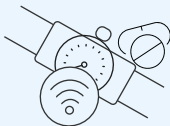
VISION



Items that help people see better or better comprehend what they cannot see.



COGNITION



Devices that help individuals who have difficulty learning, thinking, or remembering accomplish tasks that would otherwise be difficult or impossible.

MOBILITY



Devices that aid movement in space or over distance.



DAILY LIVING



Devices that assist with self-care tasks such as bathing, grooming, dressing, toileting, and feeding.



ENVIRONMENTAL



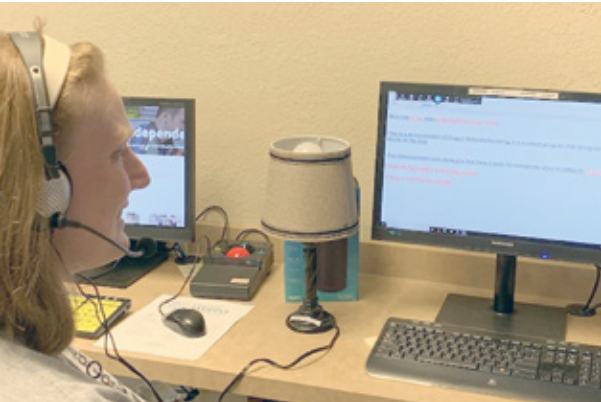
Devices that promote access to items and tools (often electronic) that are difficult to navigate.



COMPUTER ACCESS



Input and output devices, alternative access aids, modified or alternative keyboards, switches, and other hardware and software solutions that enable individuals to use a computer.



A speech-generating device gives a student the ability to communicate.



Speech input software, an alternative keyboard, and mouse alternative provide an employee with computer access.



A young woman independently completes her assignment through the combination of a tablet-based digital magnifier and text-to-speech software.

(continued on page 8)

Continuum

Assistive technology devices range in complexity and are often divided between low-tech, mid-tech, and high-tech. Low-tech devices are those that don't require much training, are inexpensive, and do not have complex or mechanical features. Mid-tech devices may require more training, usually are digital, and may require batteries and a power source. High-tech devices are typically computer based, likely to have advanced features, require considerable training, and can be tailored to the specific needs of the individual. Assistive devices do not have to be expensive or complex to be the right match for an individual. AT professionals will work along the continuum from low-tech to high-tech based on the needs of the individual.



At home, work,
school, or play, assistive
technology provides
choice, control, and
independence. But most
importantly, it makes
things possible for
people with disabilities.



Feature Matching

Feature matching is the final pillar in getting started with assistive technology. Feature matching is the process by which the elements of a device align to the user's needs based on their range of abilities. Too often, device abandonment occurs shortly after purchase because it was selected based on elements other than what the user needs. An added benefit to feature matching is that device names don't need to be remembered, just the aspects that will make them effective for the user.

The AT categories, AT continuum, and importance of feature matching provide a solid foundation on which to begin your personal pursuit of AT solutions. Set a simple goal. Select a task that presents a challenge that you wish to do easier or independently. Identify the AT category. List out the features the device needs to have and begin your exploration.

Many great online resources are available to help. The AT3Center's Explore AT is a clearinghouse for information and resources on many different assistive technologies. Find it at at3center.net/explore-at. It will help you identify AT devices and services in the environments of education, employment, and community living for all ages and functional abilities. In addition, there is a federally funded Assistive Technology Act Program located in each state. The Tech Act Programs provide a range of services from information and assistance to demonstrations, from device loans to funding assistance. Services vary by state. Access it at at3center.net/state-at-programs.



5 FACTS ABOUT PBA

Despite years of research, there is still confusion and misinformation surrounding PseudoBulbar Affect (PBA). If you suspect that you or a loved one may be affected, the first step towards treatment is an accurate diagnosis, so be sure to talk to your doctor.

- 1 Typically, PBA occurs secondary to a neurological disorder or brain injury.** PBA is commonly found in patients with a stroke, amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), traumatic brain injury (TBI), Alzheimer's disease or Parkinson's disease.
- 2 Studies have found that nearly 7.1 million Americans have symptoms** typically associated with PBA.
- 3 PBA is often confused with depression.** However, PBA is a neurological disorder, meaning that it is caused by damage to the nervous system. It is different from psychological disorders like depression and bipolar disorder that are related to a person's emotional and mental state. Because sudden emotional outbursts can be a symptom of several conditions, it is important to visit a doctor receive a proper diagnosis.
- 4 PBA episodes - including uncontrollable laughter and involuntary crying - are unpredictable.** They can occur at any time and last several seconds or minutes. Many times, these episodes can happen at inappropriate times and can cause the person and/or their caregivers to feel embarrassed and confused.
- 5 There are ways to manage PBA.** If you talk with your doctor, they can help determine which treatments may work best for you. Prior to meeting with your doctor, keep a diary to track your episodes. Remember to include if something triggered the episode, if the episode was consistent with your actual feelings at the time, and how long the episode lasted.



Financial Management Strategies for Brain Injury Survivors

Basic Tools for Navigating Money after Brain Injury

By Heather Eldridge OTR/L, CBIS

After sustaining a brain injury, individual and household financial management may become more complex. This may be a result of both internal and external factors, such as changes in cognitive function and new financial stressors such as medical bills. The following resources can help you navigate money management after brain injury.



1. Identify Your Barriers:

Naming and examining your unique challenges can help you tailor solutions to your circumstances. Common barriers faced by individuals with brain injuries include:

- Cognitive deficits: Attention, concentration, memory, learning, judgement, perception, processing, initiation, communication
- Physical setbacks: Vision, handwriting, dexterity, speech, mobility
- Environmental barriers: Support and resource availability, service accessibility

2. Take Stock:

Take inventory of your current financial situation and prioritize your needs. You can then set financial goals.

- Identify your values, hopes, wants, and dreams
- Use the “SMART Goals” system: Specific, Measurable, Achievable, Relevant, and Time-bound
- Break up goals into smaller actionable steps.
- Consider setting goals for life events and big purchases (e.g., buying a car, birth/adoption, marriage, birthdays)

3. Get Organized:

- Set up a budgeting system – Use an online, mobile, or paper budgeting system or work with a credit counselor to track income, benefits, and expenses. This can also help you reduce debt and work towards achieving financial goals.
- Set up a bill paying system – Enable autopay or use alerts, notifications, or calendar reminders for recurrent bills.
- Set up a mail management system – Consider a plan for how to sort mail. Identify what to shred, what to file, and what to act upon. Invest in a paper shredder and a filing cabinet, accordion folders, three-ring binders with pocket dividers, and/or bank boxes.

4. Set a Routine and Stick to It:

The following cadence may be appropriate: Review mail one-to-two times weekly. File paperwork one-to-two times weekly. Keep an expense journal and log receipts daily.

5. Keep it Simple:

Start small. If possible, only use one bank, one credit card, and one email address.

6. Protect Your Finances:

Consider taking a course or reading up about financial safety. Make sure to guard your identity by keeping your passwords and money safe and avoiding scams. Understand your credit report and score and know how to spot red flags. Report exploitation.

7. Review and Update Periodically:

Keep your systems current and track your financial goal progress. Return to step one periodically.

8. Look to the Future:

Advocate for your needs, consider cultivating relationships with local resources, and onboard financial local/federal supports.

Online Banking



PRO: Easier for those with reduced mobility, limited access to transportation, or difficulty with communication

CON: Requires use of and access to technology and secure internet connection

In-person Banking



PRO: Allows individuals to cultivate relationships with bank employees so that they can request accommodations

CON: Less accessible and limited hours of operation and locations

There is so much more to know about financial planning and disability. For further information, visit the Consumer Financial Protection Bureau website at consumerfinance.gov. The site offers a variety of financial management resources, including two free guides available by mail or for download online: “Your Money, Your Goals” and “Focus on People with Disabilities Companion Guide.”

Financial Supports and Resources

1. Benefits Assistance

Benefits eligibility: benefits.gov

Social Security and Medicare status: 800-772-1213
orssa.gov

2. Health Care Bills

Medicaid and Children’s Health Insurance Program (CHIP) programs: medicaid.gov

Enroll in health insurance: healthcare.gov

Medicare and State Health Insurance Programs (SHIP) programs: shiptacenter.org

3. Housing or Utility Bills

Department of Housing and Urban Development’s (HUD) Housing Counseling Office: 800-569-4287
Federal Communications Commission (FCC) for a “Lifeline” phone rate: 888-225-5322

4. Employment

Search for job: USA.gov/find-a-job

American Job Centers: 877-872-5627

5. Debt

National Foundation for Credit Counseling (NFCC): 800-388-2227

Filing complaints with CFPB: consumerfinance.gov/complaint

State Attorney General’s Office: naag.org/naag/attorneysgeneral/whos-my-ag.php

6. Legal Help

Legal resources by state: lawhelp.org

Legal Services Corporation: lsc.gov/what-legal-aid/find-legal-aid

7. Student Debt

Consumer Financial Protection Bureau: cfpb.gov/paying-for-college

Total and Permanent Disability (TPD) discharge of federal student loans: disabilitydischarge.com

8. Assistive Technology

Administration for Community Living: acl.gov/programs/assistivetechology/assistive-technology

Alternative Financing Programs by state: askjan.org/links/upload/AlternativeFinancingProgramListing.pdf

9. Identity Theft

Identity protection: identitytheft.gov

Credit reports and scores or order a free credit report: 877-322-8228 or annualcreditreport.com

Information on credit reports and scores: consumerfinance.gov/consumertools/credit-reports-and-scores

Requesting Job Accommodations after Brain Injury

Determining Limitation-appropriate Adaptations for You

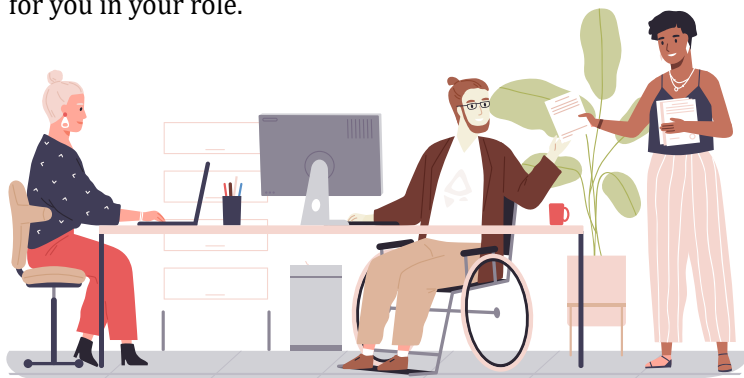
This article is adapted from the Job Accommodation Network (JAN)'s "Accommodation and Compliance: Brain Injury" web page at askjan.org/disabilities/Brain-Injury.cfm.



Every brain injury is unique and may have short-term or long-term impacts on one or more functional areas of the brain. As an individual with a brain injury in the workforce, the impacts of your injury may entitle you to accommodations to ensure that you are able to perform your responsibilities safely and effectively.

The Americans with Disabilities Act (ADA) defines "disability" in general terms. An individual is considered disabled if they have any physical or mental impairment that substantially limits one or more major life activities, has a record of such impairment, or is regarded as having an impairment. Information about this definition and the legal protections provided can be found at ada.gov.

Some individuals with brain injuries may have impairments that qualify them for work accommodation under the ADA. The following is a list of impairments and associated accommodations. These are starting points, not a complete picture of every accommodation that any individual with a brain injury might request. Discuss with your employer what may be the best path for you in your role.



Difficulty Paying Attention or Staying Organized; Reduced Executive Function

- Adjusted lighting fixtures (reduce flashing lights, change color)
- Change of office space or location to reduce distraction
- Desk organization tools such as filing cabinets, labels, binders
- Timers and watches
- Job coach
- Noise canceling headphones or earplugs
- Restructure job schedule or hours
- Telework
- Clear verbal or written instructions and deadlines from supervisors and colleagues
- Uninterrupted time blocked off on schedule
- Organizational software or apps
- Additional time to complete tasks

Fatigue

- Reduced hours
- Flexible schedule
- Telework
- Job restructuring
- Ergonomic equipment
- Assistant



Photosensitivity

- Adjusted lighting fixtures (reduce flashing lights, change color, anti-glare filters)
- Change of office space or location

Reduced Emotional Control/Stress Tolerance

- Counseling/work with HR
- Job coach
- Disability training for the rest of the team
- Positive feedback from supervisor or colleagues
- One-on-one communication
- Support animal
- Telework
- Behavior modification techniques

Seizures

- Designated responders/plan of action
- Team training and cognizance
- Flexible schedule
- Telework
- Transportation assistance
- Support animal
- Modified lighting
- Padded edging
- Protective gear
- Rest area/private space



Reduced Mobility

- Grab bars
- Canes
- Walkers
- Scooters
- Wheelchairs
- Modified workspace

The Brain Injury Association of America (BIAA) is the voice of brain injury awareness and advocacy on Capitol Hill and a strong proponent of the Americans with Disabilities Act. Sustaining a brain injury itself does not qualify you for accommodation. Accommodations are determined in direct relation to job responsibility and limitation. If you have questions about whether you qualify, or if you seek or have sought accommodation from your employer and think you have been denied wrongfully, BIAA recommends speaking with a disability rights attorney to determine the best course of action for your individual circumstances.

**Save
Our
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Resources**



Preserving access to lifesaving flights

SOAR Campaign

is committed to preserving access to emergency air medical services for the 85 million Americans who live more than an hour away from trauma centers best suited for treating brain injuries. Already faced with health disparities that put them at greater risk, rural communities can't afford to lose out on lifesaving services.

So that they don't, SOAR is working to ensure the Department of Health and Human Services updates the Medicare reimbursement rate to cover the actual cost of transporting patients in crisis.

Visit soarcampaign.com today to learn more.

FACTS

Since 2010, more than 130 rural hospitals have closed, putting more distance between patients and the nearest trauma center.

Air ambulances fill this critical gap in rural America by transporting patients quickly and safely.

 @SOARCampaign

Brain Injury Advocate Leaves Lasting Legacy

By Robbie Baker, Vice President and Chief Development Officer, Brain Injury Association of America

Dr. Shelly Levy will be remembered for her dedication to the brain injury community

In February 2020, the brain injury community lost a powerful friend and advocate. Dr. Shelly Levy was a highly regarded specialist and leader in the field of brain injury and substance use treatment. In addition to her numerous committee appointments and volunteer efforts, Dr. Levy served on the steering committee of the Brain Injury Association of New York State, New York City Chapter since its inception in 2011.

Dr. Levy began her career by providing direct care and psychological assessment services for individuals with developmental disabilities in residential, day treatment, and school settings, ultimately expanding her practice to include treatment of substance use problems in individuals with both intellectual disabilities and brain injury challenges. Dr. Levy trained thousands of mental health and substance use professionals on the problems and treatment associated with brain injury and co-occurring substance use disorders. She was instrumental in the development of the first community-based neurorehabilitation program for adults with brain injuries in New York City.

A fierce advocate for social justice and access to care, Dr. Levy was dedicated to increasing awareness about the brain injury community. She loved her work, and in particular, the individuals and colleagues with whom she worked. Says fellow volunteer Laurie Rippon, “So many of us were isolated, hungry to be seen, heard, and respected. Shelly, who lived with brain injury but didn’t have one, believed in us.”

Dr. Levy’s love for her patients and the brain injury community transcended her own health. Says friend and colleague Dr. Catherine Mindolovich, “One of the last wishes Shelly expressed was to return to her clients and continue her efforts despite her own medical difficulties



Dr. Shelly Levy


at the time. She remained concerned about her clients and their well-being until the very end of her own life.”

Dr. Levy further expressed her devotion to the brain injury community by making a provision for the Brain Injury Association of America (BIAA) in her estate plan providing for future generations of survivors, caregivers, and brain injury specialists. On Arbor Day 2022, friends and colleagues planted a tree in Dr. Levy’s memory in Brooklyn’s Prospect Park.

A Legacy with Lasting Benefit

Thanks to friends like Dr. Levy who make charitable provisions in their will or estate plan, BIAA is able to invest in new lines of services and meet the ever-evolving needs of the brain injury community.

For more information about how you can include BIAA in your will or estate plan and be recognized as a member of the Futures Fund Legacy Society, visit biausa.org/futuresfund or contact Robbie Baker, Vice President & Chief Development Officer at (703) 761-0750, ext. 648 or rbaker@biausa.org.



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biausa.org/attorneys

The Voice of Brain Injury

The Brain Injury Association of America is the country’s oldest and largest nationwide brain injury advocacy organization. Our mission is to advance **awareness, research, treatment, and education** and to **improve the quality of life for all people affected by brain injury**. We are dedicated to increasing access to quality health care and raising awareness and understanding of brain injury.



Learn more at biausa.org



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The Futures Fund Legacy Society recognizes donors who have made a provision for BIAA through a planned gift or in their will or estate plan. Legacy gifts make it possible for BIAA to be able to invest in new lines of research and meet the ever-evolving needs of the brain injury community. A special thank you to the following individuals who have made such thoughtful commitment.

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ADVOCACY UPDATE

By Susan Connors, President/CEO, Brain Injury Association of America

This year is fast becoming a banner year for federal policy affecting individuals who have sustained brain injuries. Here are a few brief highlights:



Long COVID

In April, President Joe Biden released a Presidential Memorandum charging Health and Human Services (HHS) Secretary Xavier Becerra with leading a “whole-of-government” effort to address the Long COVID crisis. The Memorandum directs Sec. Becerra to develop and issue the first-ever interagency national research action plan to advance progress in prevention, diagnosis, treatment, and provision of services, supports, and interventions for individuals experiencing Long COVID and associated conditions.



The Memorandum also directs HHS to issue a report outlining services and supports across federal agencies to assist people experiencing Long COVID, individuals who are dealing with a COVID-related loss, and people who are experiencing mental health and substance use issues related to the pandemic. This report will specifically address the long-term effects of COVID-19 on high-risk communities and disparities in access to services and supports.

The President’s Fiscal Year 2023 Budget Request proposes funding to carry out the work by the Department of Defense, Veterans Administration, and Centers for Disease Control and Prevention, among other agencies.

Improving Seniors’ Timely Access to Care Act

The Improving Seniors’ Timely Access to Care Act was introduced by Senator Roger Marshall (R-Kan.) and Representative Suzan DelBene (D-Wash.) with 22 cosponsors in the Senate and 278 cosponsors in the House. This legislation seeks to modernize prior authorization rules in Medicare Advantage plans by:

- Establishing an electronic prior authorization process to streamline decisions,
- Establishing national standards for clinical documentation to reduce administrative burdens,
- Creating a process for real-time decisions for routine services,
- Increasing transparency and communication across all parties, and
- Requiring beneficiary protections to serve seniors first.

According to the Regulatory Relief Coalition, these changes are necessary because prior authorization is the “#1 administrative burden” providers face. Nearly 80% of Medicare Advantage (MA) enrollees are subject to unnecessary delays in treatment. The Office of Inspector General found 75% of treatment requests that were initially denied were eventually overturned. The Medicare Payment Advisory Commission (MedPAC) reports that MA patients have one-third access to inpatient rehabilitation facilities as compared to traditional Medicare patients.

The Brain Injury Association of America (BIAA) strongly supports the Improving Seniors' Timely Access to Care Act because we believe rehabilitation of sufficient scope, duration, and intensity is the single most effective way to stop, slow, or reverse the disease-causative and

disease-accelerative processes brought on by brain injury. BIAA believes rehabilitation is the only way to regain lost function and improve health outcomes. To the extent that treatment is delayed or denied altogether, individuals are robbed of the opportunity to return to lives as close to pre-injury as possible.



Brain Injury from Intimate Partner Violence

In March, Congressional Brain Injury Task Force Co-chairs Reps. Bill Pascrell, Jr. (D-N.J.) and Don Bacon (R-Nebr.) and Sens. Catherine Cortez Masto (D-Nev.) and Joni Ernst (R-Iowa) introduced H.R. 7301 and S. 3962 to authorize HHS to collect data on the prevalence of brain injuries resulting from intimate partner violence (IPV) and sexual assault. The U.S. General Accountability Office (GAO) recommended enhanced data collection based on state and national investigations of brain injury due to intimate partner or domestic violence. BIAA supports these bills.

The BRAIN Act

The Bringing Regulatory Advances Into Neuroscience (BRAIN) Act would establish a Neuroscience Center of Excellence at the Food & Drug Administration. Similar to the Brain Initiative within NIH, the Neuroscience Center at the FDA would move away from disease or injury specific studies to try to cross-pollinate neurologic and psychiatric discoveries to benefit the whole brain. Initial appropriation authorized is \$25 million.

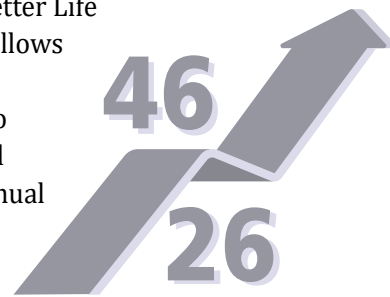


Law Enforcement Training Act

The Traumatic Brain Injury and Post Traumatic Stress Disorder Law Enforcement Training Act (H.R. 2992), introduced by Rep. Bill Pascrell, Jr. (D-N.J.) and co-sponsored by Reps. Don Bacon (R-Neb.), Val Demings (D-Fla.), and John Rutherford (R-Fla.), passed the House May 18, 2022. The bill requires the Justice Department to create crisis intervention training tools for police officers confronting individuals with brain injuries or post-traumatic stress. The tools will be part of the Police-Mental Health Collaboration Toolkit. The bill also requires the CDC to study the incidence and prevalence of concussions among first responders. BIAA and the Fraternal Order of Police have endorsed the legislation. Sens. Chuck Grassley (R-Iowa) and Jon Ossoff (D-GA) introduced a companion bill in the Senate.

ABLE Age Adjustment Act

The 2014 Achieving a Better Life Experience (ABLE) Act allows individuals who become disabled before age 26 to establish tax-advantaged saving accounts with annual contributions of up to \$16,000. As long as the accounts do not exceed \$100,000, eligibility for most public programs is not impacted. Originally, only people who became disabled before age 26 could have ABLE accounts. The ABLE Age Adjustment Act, introduced by Sen. Robert Casey (D-Pa.) and Rep. Tony Cardenas (D-Calif.), would raise the age limit to 46. The legislation has now been included in the Encouraging American Retirement Now (EARN) Act and is headed to the Senate for consideration.



BIAA Launches Legislative Action Center

BIAA's new online advocacy tool makes it easy for grassroots constituents to send pre-written, targeted messages to their members of Congress. To see the tool in action, please visit biausa.org/legislative-action-center.



STATE AFFILIATE NEWS

Alaska

In 2022, the Alaska Brain Injury Network (ABIN) restructured to become the newest chartered affiliate of the Brain Injury Association of America (BIAA). We are repositioning to build communities of care across Alaska, a studio capable of delivering informed content, and a web presence with partnered content to support the needs learned from these communities and their members. The Alaska State Plan for Brain Injury (July 2020 – June 2025), held by the Alaska Traumatic and Acquired Brain Injury (TABI) Advisory Council, contains highlights of the prior work of ABIN started nearly 20 years ago and now flourishes with the TABI outreaches by the State of Alaska, the University of Alaska, and various nonprofit organizations.

Now known as the Brain Injury Association of Alaska (BIA-AK), the organization is restructuring into a two-pillar model where one pillar focuses on BI survivors and those that care for them spread out across the State of Alaska. Independent Communities of Care (ICCs) exist to teach local communities how to "be there for one another," and ICCs work with BIA-AK learning to walk

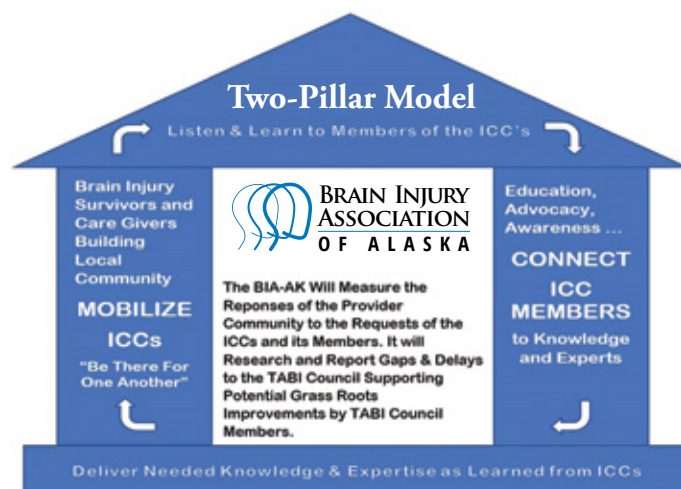


Illustration of the Brain Injury Association of Alaska's two-pillar model.

life together. The second pillar connects individuals with brain injury with education, advocacy, and awareness to improve the quality of life. Repositioned, BIA-AK serves Alaskans impacted by brain injury and those seeking to enhance everyone's quality of life!

Our support comes from those that value what we do. If you want to help us in these early stages, visit our website at BIAAK.org and donate.

Georgia

The Brain Injury Association of Georgia (BIAG) is excited to announce personnel changes for 2022. Cassandra Palmer has accepted the role of executive director, taking over for Jane Jackson. Cassandra brings a professional background in working with Medicare, Worker's Compensation, and health benefits compliance regarding patient advocacy for health claims. Cassandra has also been a caregiver and a support group leader for BIAG since 2018.

Jane Jackson served as the BIAG's executive director for 20 years. She has accepted the position of resource facilitator director for the newly established Resource Facilitation program that is made possible by a grant from the Brain and Spinal Injury Trust Fund Commission of Georgia. The grant program is headed by Kenisha Tait, traumatic brain injury grant program manager, and Craig Young, executive director. BIAG and the Trust Fund have been working diligently since August 2021 to launch this five-year program with the goal of helping people with traumatic brain injury when insurance and services fall short. Resource Facilitation during the five-year grant cycle will provide those who are injured with a counselor to provide support over the course of two-plus years.



Cassandra Palmer

Louisiana

During Brain Injury Awareness Month, the Brain Injury Association of Louisiana (BIALA) presented its 13th annual conference, “Together Toward Tomorrow.” Throughout the two-day event, over 200 allied health professionals, caregivers, and individuals living with brain and spinal cord injuries gathered and had the opportunity to advance their knowledge and to learn together. A survivor track was offered with presentations that included how to be a self-advocate, the importance of recreation in one’s life, understanding technology, fit and fun chair exercises, and how to approach recovery as an explorer. Following the presentations, a Survivor Social was held and some great giveaways were provided. A high level of energy and excitement ran through the exhibit hall where 34 sponsors and exhibitors were thrilled to share new information on products, services, and available resources.

Throughout the past year and a half, BIALA and Tulane University’s Department of Theatre and Dance Documentary Theatre have partnered to raise awareness about brain injuries through a service-learning project. Students interviewed individuals with brain injuries, caregivers, and brain injury rehabilitation professionals to deepen their understanding of how it feels to live with and work with brain injuries. These interviews were used to create a documentary where the students shared the thoughts and feelings gleaned from these individuals. To create further awareness and understanding about living with brain injuries, the Tulane students turned their documentary into an impactful and moving performance where they “brought to life” these interviews. The performance, titled “Live Life in Color,” was presented during the conference and moved many to tears. “Live Life in Color” was a highlight of the event leaving all who attended with a much deeper and more respectful understanding of the impact of a brain injury. To view the performance, visit [instagram.com/tv/CbiNNTkgy5A](https://www.instagram.com/tv/CbiNNTkgy5A).



Students with Tulane University’s Department of Theatre and Documentary Dance Theatre present “Live Life in Color” during BIALA’s annual conference.



Individuals with brain injuries, their caregivers, and professionals gather for BIALA’s two day annual conference.

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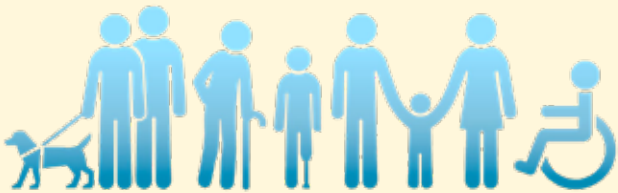
Maine

The Brain Injury Association of America – Maine Chapter (BIAA-ME) is looking forward to its 13th Annual Conference on Defining Moments in Brain Injury, which will take place Sept. 27, 2022, at the Holiday Inn by the Bay in Portland. This premier event is centered on research, treatment, and services pertinent to brain injury recovery and rehabilitation in Maine.

BIAA-ME also continues to partner with the State of Maine’s Office of Aging and Disability Services (OADS) on a TBI Partnership Grant from the Administration for Community Living and with Speaking Up For Us on a two-part virtual presentation series on brain injury and self-advocacy.

Massachusetts

In August, the Administration for Community Living (ACL) awarded a five-year federal grant to the Massachusetts Rehabilitation Commission (MRC) in partnership with the Brain Injury Association of Massachusetts (BIA-MA), the Massachusetts Department of Public Health (MDPH), and the Massachusetts Department of Mental Health (MDMH) to fund Beyond Bridges.



The grant will ensure the presence of a strong and engaged state Brain Injury Council to guide the Beyond Bridges Project through collaborative leadership between partnering state agencies and providers. The Brain Injury Council will update the State Plan for services and supports for individuals to reflect the identified needs of the diverse brain injury population. Under the grant, the state will improve TBI resource facilitation systems to focus on behavioral health services through workforce development, professional education, community awareness, and enhanced peer groups.

Missouri

The Brain Injury Association of Missouri (BIA-MO) “Sports Concussions: Fact, Fallacies, and New Frontiers” seminar was held online Feb. 25, 2022. Sessions focused on research updates, light physical activity as part of recovery, and supporting youth with non-sports concussions. Similarities of Long COVID and concussions were discussed. Participants included youth sports coaches, recreational league staff, and school personnel.

For Brain Injury Awareness Month, BIA-MO conducted a Brain Injury Fact of the Day media campaign in partnership with Missouri AgrAbility. A unique Brain Injury Fact was posted on news, weather, health, agriculture, and veteran social media and websites. Postings encouraged individuals to visit BIAMO.org to learn more.

BIA-MO Survivor and Family Seminars were held online March 26 and April 2, 2022. There was an interactive session of survivor-friendly movements and mindfulness for exercises, relaxation, and fun. Another session focused on how different habits, foods, and activities affect your brain, actions, and daily life. The importance of keeping a routine, organizing your surroundings, and composing your thoughts was discussed. Survivors of brain injury received information about ways to communicate their needs and wants at every stage of recovery.



BIA-MO Camp is not complete without tie-dyeing shirts.

One-Day Regional Outdoor Camps were held in Columbia (June 26), Kansas City (June 12), Springfield (June 26), and St. Louis (June 25). Activities included arts and crafts, tie-dyeing, music, games, and food.

Bowling for Brain Injury was held June 11 (Kansas City) and June 18 (Springfield and St. Louis).



Bowling for Brain Injury proceeds support BIA-MO services.

New Hampshire



Stacia Bissell

The Brain Injury Association of New Hampshire (BIANH) held their 39th Annual Brain Injury and Stroke Conference on May 11, 2022 in Concord. Keynote Speaker Stacia Bissell presented “Creating a Collaborative Team to Help You Return to Work.” Stacia became a licensed middle and high school principal in 2011, however, a bicycle accident later that same year left her with a traumatic brain injury and ended her career as a public-school educator. Other features at the conference included a special COVID track, brain injury and mental health, vision therapy, dysphagia after a stroke, and more.

The 36th Annual Walk by the Sea and Picnic was held at Hampton Beach State Park on June 5, 2022. The annual golf tournament will be held in August at The Oaks Golf Course in Somersworth. Survivor Jason Schreck will share his story of rehabilitation and recovery. The golf tournament is a popular event for BIANH with over 100 golfers participating and strong sponsorships.

Pennsylvania

On March 29, 2022 the second annual Brain Injury Awareness Day was held at the Pennsylvania State Capitol Building in Harrisburg. The day started with a Rally in the Rotunda, a truly inspiring space! Senators Ryan Aument and Tim Kearney spoke about their commitment to keeping the issues affecting individuals with brain injury and their family members in mind as they do their day-to-day work in the legislature. They serve as co-chairs of the Brain Injury Caucus, along

with Representatives Tina Pickett and Tim Briggs, who spoke at a reception in the afternoon. Stefanie Bauman provided educational information about brain injury in her address to the group. Kevin McDonald and Melissa Carmen, survivors of brain injury and organizers of the event, told their stories to inspire the group and bring the issues experienced by individuals with brain injury to life.

(continued on page 28)



SEASON 2 EPISODE 7



Brain Injury Awareness Day 2022 Harrisburg, Pennsylvania

Many attendees made visits to their legislators over the course of the day to educate them about issues affecting individuals in Pennsylvania with brain injury. Drew Nagele, Psy.D., CBIST, FACRM, facilitated a panel discussion on brain injury in the afternoon, and the day closed with a reception.

One feature of the day was a podcast hosted by Candace Gantt of the Mind Your Brain Foundation and recorded live in Senator Kearney's office. The podcast includes comments from Senator Kearney, Pennsylvania Brain Injury Caucus co-chair; Melissa Carmen and Kevin McDonald, brain injury survivors and organizers of the event; Ann Marie McLaughlin, BIAPA president; and Drew Nagele, co-chair of the Pennsylvania Brain Injury Coalition. You can access the podcast at anchor.fm/mindyourbrainfoundation. Click on Season 2: Episode 7.

South Carolina

The Brain Injury Association of South Carolina (BIASC) coordinated an art project to present to our state legislators during Brain Injury Awareness Month. A popular pastime, river rocks are painted and hidden all over the country with notes to return them to their destination or post on rock community pages with notes about where they were found. They are often painted in memory of a loved one or have inspirational words painted on them. Brain injury advocates wanted to leave our legislators a tangible reminder of the importance of brain injury awareness and keeping organizations like BIASC in the state budget to assist with our awareness, prevention, and education efforts.



BIASC volunteers, staff, board members, and brain injury survivors delivered an awareness rock to South Carolina Senator Penry Gustafson (pictured in the black and white dress) in her office at the state house.



Awareness rocks with BIASC stickers on the bottom painted by brain injury survivors.

BIASC provided river rocks and supplies to brain injury support groups, rehabilitation hospitals, outpatient programs, and day programs for their brain injured patients to paint. We needed 170 rocks to have enough for each of our legislators and received well over that amount. The facilitators and therapists reported the activity was very therapeutic for the survivors as well as fun!

On March 3, BIASC staff, volunteers, and brain injury survivors delivered the awareness rocks to legislators and their staff. Survivors told their stories and listened to legislator and staff experiences as well. It was a great experience for everyone. We hope to make it an annual event during Brain Injury Awareness Month!



BIASC representatives, Phoenix Center staff, and brain injury survivors posed for a group picture on the state house grounds after delivering awareness rocks to each legislator's office.

Virginia

For the Brain Injury Association of Virginia (BIAV), the last three months put brain injury awareness and advocacy center stage. Alongside other brain injury providers and community advocates, BIAV hosted our 2022 Phone a Friend at the General Assembly campaign. Brain injury advocates called, emailed, and sent letters to Virginia state legislators and members of the budget committees to ask them to support two budget amendments that would expand funding for housing services and community-based brain injury case management services. We generated more than 85 emails, letters, and calls to legislators from brain injury survivors and over 80 emails, calls, and letters from brain injury advocates such as family members and program staff.

While advocates were reaching out to legislators via phone, BIAV staff met with more than 10 legislators in person. In these meetings, we discussed how these budget amendments would continue to make Virginia a better place for people with brain injuries and their families.

This advocacy continued in the BIAV office through the development of our Housing Professional's Guide to Brain Injury. This guide was designed to educate homeless services providers on brain injury, identifying brain injuries, and how to help clients if they have a brain injury. After the release of this guide, the level of confidence of housing professionals to identify brain injury symptoms increased by 22%, and now over 75% of providers know where to find a brain injury resource. Provider's knowledge on the link between homelessness and brain injury increased by 25% after receiving these resources.

BIAV highlighted this project and more through Brain Injury Awareness Month. The More Than My Brain Injury campaign in Virginia not only highlighted the stories of Virginians living with brain injury, but also educated the public about multiple factors of brain injuries (e.g., domestic violence, grief) and the programs and resources BIAV has available.

To learn more about our programs, please visit us at BIAV.net.



From left to right: Deputy Director Tim Williams, Community Brain Injury Services Executive Director Jason Young, Delegate Emily Brewer, BIAV's Executive Director Anne McDonnell, and Delegate Sam Rasoul

Let's Stay in Touch



Get brain injury updates in your email inbox. Sign up for one of our mailing lists!

- **ADVOCACY** – Action alerts and our weekly Policy Corner newsletter
- **EDUCATION** – Information about upcoming webinars, conferences, and other learning opportunities
- **GENERAL** – Brain injury resources, BIAA updates, and even digital copies of *The Challenge!*
- **RESEARCH** – The latest information about brain injury research, including our own grant program



biausa.org/signmeup

UPCOMING **WEBINARS**

David Strauss Clinical Memorial Lecture – Self-Awareness after TBI

July 14, 2022, 2:00 p.m. ET/ 11:00 a.m. PT

Whitney Neal, Ph.D., CCC-SLP

David Strauss Clinical Memorial Lecture – Realities of Recovery Journey for Children and Adolescents after Brain Injury

July 28, 2022, 3:00 p.m. ET/12:00 p.m. PT

Jennifer P. Lundine, Ph.D., CCC-SLP

Carolyn Rocchio Caregivers Webinar– Estate Planning for Families of Individuals with a Brain Injury

August 11, 2022, 3:00 p.m. ET/12:00 p.m. PT

Keith Miles, Esq.

Carolyn Rocchio Caregivers Webinar- Emotional and Behavioral Changes following Pediatric Brain Injury: An Overview

August 18, 2022, 3:00 p.m. ET/12:00 p.m. PT

Danielle Ploetz, Ph.D.

**To register, please visit
shop.biausa.org/livewebinars.**

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Center for Neurologic Study-Lability Scale (CNS-LS) for Pseudobulbar Affect (PBA)

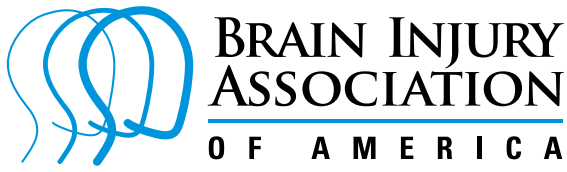
The CNS-LS is a short questionnaire that can help individuals with neurologic illness or injury identify the presence of PBA symptoms and their frequency. After a week of tracking, patients can share the questionnaire with their physicians.



Patient assessment	Applies never	Applies rarely	Applies occasionally	Applies frequently	Applies most of the time
There are times when I feel fine one minute, and then I'll become tearful the next over something small or for no reason at all	1	2	3	4	5
Others have told me that I seem to become amused very easily or that I seem to become amused about things that really aren't funny.	1	2	3	4	5
I find myself crying easily.	1	2	3	4	5
I find that even when I try to control my laughter, I am often unable to do so.	1	2	3	4	5
There are times when I won't be thinking of anything happy or funny at all, but then I'll suddenly be overcome by funny or happy thoughts.	1	2	3	4	5
I find that even when I try to control my crying, I am often unable to do so.	1	2	3	4	5
I find that I am easily overcome by laughter.	1	2	3	4	5

Source: Moore, SR et al. J Neurol Neuro J Neurol Neurosurg Psychiatry. 1997;63(1):89-93.

NOTES: _____



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The Corporate Partners Program gives rehabilitation providers, long-term care facilities, attorneys, and other leaders in the field a variety of opportunities to support the Brain Injury Association of America's advocacy, awareness, information, and education programs. BIAA is grateful to the Corporate Partners for their financial contributions and the many volunteer hours their companies devote to spreading help, hope, and healing nationwide.

For more information on how to become part of the Brain Injury Association of America Corporate Partners Program, please visit biausa.org/corporate or contact Carrie Mosher at 703-761-0750, ext. 640 or cmosher@biausa.org.

